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ABSTRACT

Three demonstration models of advocacy programs for developmentally disabled children and their families are reviewed by the United Cerebral Palsy Associations, Inc. In a general summary statement, advocacy is defined as responsibility for seeing that legal and human rights are met; the history, rationale, and future plans for the 5-year Child Advocacy Project are given; and problems (such as lack of service at the appropriate time), goals, objectives, and strategies for overcoming barriers to services and resources are described. The Milwaukee Advocacy is seen to be an agency advocate/ombudsman model serving a predominantly black inner city population, with a legal advocacy program as one projected outcome. The San Mateo/Santa Clara (California) Model is described as a consumer advocacy model involving young, poor Chicanos in planning and developing community services. Comments on the New York State program (an agent advocate/program developer model) center on objectives, such as preparing legislative proposals, to meet the needs of populations in rural areas and state institutions. Discussed in the second component of the document are major goals, secondary objectives, and rationale for the National Advocacy Project as a whole and for the three models. (LH)

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# A Demonstration of Three Models of Advocacy Programs for Developmentally Disabled Children

United Cerebral Palsy Associations, Inc., launched its Child Advocacy Project in July, 1972. This project is a conscious effort to learn about the processes of advocacy so that the organization may be able to more quickly obtain services and resources for persons with cerebral palsy and other developmental disabilities. Funding for the project is being received from three agencies of the federal government -- Bureau of Education for the Handicapped, National Institute of Mental Health and Rehabilitation Services Administration.

For UCPA., Inc., advocacy means that someone takes responsibility for seeing that the legal and human rights of the person with a developmental disability and his family are met. These include the rights to education, property, Community services, employment, social involvement and other necessities of life as well as medical and therapeutic care. Child Advocacy for the organization becomes increasingly important when the individual and his family are unable to assume all or part of these responsibilities. Advocacy concepts were first outlined in the IHF Plan(Individual with Cerebral Palsy and His Family) developed by UCPA., Inc., in 1968.

Three affiliates of UCPA., Inc., are participating in the project and contributing their funds on a matching basis. UCP of New York State, UCP of Southeastern Wisconsin(Milwaukee) and UCP of San Mateo Co./Santa Clara County(California) were selected to develop the demonstration advocacy models on the criteria that they represent diverse geographic and population differences, areas with varying patterns of service delivery and availability, and unique patterns of program within the affiliate.

The goals, objectives and strategies for the three models of advocacy have evolved from a number of specific problems which include getting services at the time they are needed, being discriminated against in receiving generic community services, lack of service and resource development, terrible living conditions in state institutions, plus problem associated with poverty and racism. There is an attempt to change the status-quo in many areas of decision making or power by involving individuals who are historically powerless through seeking a level of increased visibility and power. Fact-finding and systems analysis dealing with attitudinal barriers, lack of accountability to consumers within service delivery systems and other factors that place people into positions of unequal opportunities are a part of the advocacy process for developing strategies to overcome the barriers to service and resources.

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The Milwaukee Advocacy Model can be described as the Agency Advocate/ Ombudsman Model. This model includes components of an ombudsman program offering individualized services, a consumer information program, legislative and governmental activities, fact finding and community organization functions. Among projected outcomes are a neighborhood advocate program in the inner city which has a predominent black population; a legal advocacy program; improved comprehensive follow-along services for high risk infants; improved resources and services for the severely developmentally disabled including special community residential facilities and increased opportunities for recreation.

The San Mateo/Santa Clara (California) Model can be described as the Consumer Advocacy in Community Planning Model. Components of this model include systems analysis of services, program and consumer groups; planning for case finding and program development activities; development of forums for consumer interaction with service delivery and planning units; role expansion of the case advocate and community organization functions. The projected outcomes are to get younger, poorer and ethnic minority(predominently Chicano) consumers involved in the planning and development of services and resources in order to make systems more useful and accountable to the consumer and expanding California's resources and services for the mentally retarded to include other developmentally disabled.

The New York State Advocacy Model can be described as the Agent Advocate/ Program Developer Model. Components are legislative activities, developing mechanisms for the planning and expansion of services among unserved and underserved populations in rural areas and state institutions; increasing the advocacy role of the fourteen UCP Home Service Directors and organization of consumer advocacy groups. Projected outcomes are newly developed or expanded programs; increased community placement of institution residents; and an improved communication system of unified action among consumers, UCP of New York State and legislative/administrative governmental bodies in order to solve the many problems in developing resources and services as well as focusing upon the civil rights of the disabled.

The project has stimulated many activities of national scope including cooperative advocacy ventures with other national agencies, organizations and advocacy projects. Program proposals concerning UCPA., Inc's responsibilities to its consumers are being generated to include early idenfication and referral, legal advocacy, legislative actions and increased/diverse consumer involvement at decision making levels. All national activities are directed toward increasing the existing advocacy role of UCPA Inc.

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The project design not only includes the development of three advocacy models with national coordinating functions but plans for replication of the various model components in other UCP affiliates during the fourth and fifth years of the project.

Prepared by: Marie L. Moore
National Advocacy Coordinator
January 16, 1974.

A DEMONSTRATION OF THREE MODELS OF ADVOCACY
FOR DEVELOPMENTALLY DISABLED CHILDREN

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One of the imperatives of U.C.P.A., Inc., is that a lifetime partnership should be established between an individual with cerebral palsy and his family so that the U.C.P. affiliate will serve as a permanent resource. This partnership has been expanded to those individuals with developmental disabilities who have similar service needs.

This goal is enhanced by the development of three demonstration models of advocacy programs that could be adopted by any of the 300 affiliates and other voluntary health organizations. The demonstration sites were selected using the following variables and criteria:

A. Population differences -- rural, suburban, urban areas within three distinct geographic locations and levels of Government; representing a variety of socio-economic and racial-cultural groups.

B. Varying patterns of service availability and delivery

C. UCP affiliates with their own unique organizational pattern and program.

The three models of child advocacy being developed have as a focus getting children with developmental disabilities into the appropriate services to meet their needs at the time these services are needed. The target populations are those individuals and their families who are among the underserved and unserved due to the following reasons:

Lack of services in the geographic area (usually rural or inner city areas).

Restricting criteria for admission to programs (e.g. -- consumer does not meet the physical, intellectual, sensory or financial requirements).

Services are restricted by number in caseload -- thus long waiting lists develop.

Lack of referral services to appropriate programs at the appropriate time even when comprehensive diagnostic services are available.

Lack of casefinding and follow-along services among minority groups.

Lack of consumers participation in community organization and planning -- especially among those consumers who are not affluent or influential and those with substantial handicapping conditions.

Lack of coordinated planning and services for placement or retention in the community versus institutionalization.

# NATIONAL ADVOCACY PROJECT

GOAL I:

To assist children with developmental disabilities and their families in obtaining needed services and to make the best use of available resources.

RATIONALE:

Most communities in the United States have available services in varying degrees for children with developmental disabilities and their families. It has been the experience of United Cerebral Palsy Associations, Inc., and its affiliates that parents have had difficulty in finding and locating appropriate services at the time services are needed. The proper utilization of available services has been difficult because the needs and problems of the developmentally disabled are multiple in nature. Problems are particularly acute in areas where there are families from low income and minority groups. There are also many family members who have hesitated to demand more appropriate services for those children residing in public institutions for fear, be it real or imaginary, of retaliation against their children. Children with developmental disabilities are frequently subject to many forms of discrimination when attempting to receive community based services available to the general public.

OBJECTIVE A:

To provide technical assistance upon request to those UCPA affiliates which have advocacy programs serving individuals with developmental disabilities and their families.

RATIONALE:

Several UCPA affiliates have planned to implement advocacy programs based on needs assessments of the developmentally disabled in their localities. They have developed funding sources for this purpose. The affiliates are requesting technical assistance from the national staff regarding various components of these advocacy programs which will assist the developmentally disabled and their families in obtaining needed services.

OBJECTIVE B:

To promote the advocacy role of those affiliates located in the geographic areas where there are other federally-funded Child Advocacy Demonstration Projects, in terms of the services of the demonstration projects relative to the needs of UCPA consumers.

RATIONALE:

Those children with developmental disabilities and their families who live in the localities where there are other federally funded child advocacy demonstration projects qualify for services within the project component of programs for handicapped children. Since the developmentally disabled in these catchment areas have needs and problems that are similar to other children, they require advocacy services. The

UCP affiliates are in the position to refer these children and their families to the project and work with the consumers to insure that services and resources are fully utilized.

OBJECTIVE C:

To provide technical assistance, upon request, to those affiliates expressing an interest in developing or increasing their advocacy role.

RATIONALE:

Many UCP affiliates are examining their function relative to the concept of the affiliate establishing a lifetime partnership with the individual with cerebral palsy and his family. As our society becomes more complex in organizing service delivery systems, the need becomes greater for developing expertise in helping people with multiple problems to get services they need. Some affiliates have or are developing Information, Referral and Follow-Along programs and direct services for home management. However, most programs become limited in their effectiveness unless there is an increase of the advocacy role of the affiliate on both a case and class basis.

GOAL II:

To improve the service delivery systems for the developmentally disabled at local, state and national levels by developing and promoting program and legislative proposals.

RATIONALE:

The services needed by the developmentally disabled include education, vocational planning, residential, transportation, legal, social, financial assistance, health and many others. Within service delivery systems, there are many factors which inhibit meeting the needs of the developmentally disabled. Some of these factors include the multiple problems of the consumer with a developmental disability or else the systems themselves are closed except to clientele with specific problems, needs or qualifications. Often systems are designed and administered for the convenience of those who deliver the service instead of those who receive the service. Thus many systems discourage active participation on the part of persons needing service. The dehumanizing qualities of the administrative procedures frequently require unwarranted demands on the consumer if he is to receive any services. In order to make service delivery systems more responsive to greater number of people with a variety of complex problems, it is necessary to plan for dynamic change and adopt an advocacy position for the implementation of change within existing or new systems. Program and legislative proposals -- whether they suggest simple or complex changes -- are needed in order to facilitate appropriate change for developing, expanding or recognizing service delivery systems that are more responsive to meeting the needs, minimizing the problems or insuring the rights of the developmentally disabled.

OBJECTIVE A:

To collect and analyze data regarding the service needs of the developmentally disabled.

RATIONALE:

Data of various kinds is needed for the identification and justification of needed change.

OBJECTIVE B:

To develop, disseminate and promote program proposals which address the priority needs of the developmentally disabled as determined by the National Advocacy Advisory Council.

RATIONALE:

Discriminatory practices toward the developmentally disabled must be identified and dealt with if appropriate change is to be instituted. Priority needs of the developmentally disabled must be developed if change is to be instituted despite limitations in resources including available finances, man power and technology. Since it is necessary to consider multiple resources for implementing effective change, program proposals developed in the project need to be disseminated and promoted where they will have the greatest impact for change.

OBJECTIVE C:

To develop and promote legislative proposals which address the priority needs of the developmentally disabled, as determined by the National Advocacy Advisory Council.

RATIONALE:

As our society becomes more complex, there is a need to have sufficient legislation addressed to human need in an ever changing society. Within the democratic system, legislation with adequate financial appropriations and implementation plans can fill gaps and eliminate barriers that currently exist in services to the developmentally disabled.

OBJECTIVE D:

To impact upon the UCPA, Inc. and its affiliates by advocating for the improvement and expansion of its service delivery system to the developmentally disabled.

RATIONALE:

The UCPA organization has been limited in both scope as well as quality

of services in meeting the needs of individuals with cerebral palsy and others with similar service needs. The priorities and procedure of program development as documented in the IHF Plan(Individual with Cerebral Palsy and His Family) have not been implemented throughout the country in a total national effort. The total needs of individuals versus a narrow focus on the disabling condition must be recognized in terms of social change and human development.

OBJECTIVE E:

To cooperate with other organizations and advocacy projects, both public and private in the development of strategies for the improvement of services to the developmentally disabled.

RATIONALE:

Various organizations have found it to be more effective to pool their resources, political clout, and combined expertise for the purpose of facilitating positive change. Since UCPA is a recognized organization, its advocacy clout can be used where possible to cooperate with and influence other national organizations to use their resources where appropriate for the benefit of the developmentally disabled.

GOAL III:

To increase the advocacy role of consumers* through their participation at all levels of planning, policy-making and monitoring of UCPA activities and programs.

*Consumer is defined as the individual with a developmental disability and his family.

RATIONALE:

Historically, the participation of consumers in the affairs of UCPA has been that of parents who are among the affluent and influential in our society. Those consumers who are adults with developmental disabilities or parents of disabled children -- especially among the poor and ethnic minority groups -- have had minimal involvement in the planning and decision making processes that control their own destiny. Considerations regarding their participation have been clouded by questions relative to their level of competency for judgment, problem solving and decision making experiences. The trend has been to disregard these consumers on the assumption that they are basically incapable of making contributions for a variety of reasons. However, programs developed and issues addressed without the total and ongoing involvement of the persons who are experiencing needs and problems fail to have a maximum constructive impact upon the lives of the consumers.

OBJECTIVE A:

To increase the number of consumers and consumer representatives on UCPA boards, councils, committees and task forces at local, state and national levels.

RATIONALE:

Token representation has little or no value. Unless there are sufficient numbers of consumers represented at all levels of planning, and decision making, the broad issues relative to the needs of the developmentally disabled cannot be clearly identified, defined or addressed.

OBJECTIVE B:

To diversify consumer representation within UCPA from various ethnic, cultural and socio-economic groups.

RATIONALE:

Representation from only one segment of a population cannot plan and implement programs that are beneficial and needed by all segments of a population.

GOAL IV:

To demonstrate the replicability of the components of the UCPA Child Advocacy Project.

RATIONALE:

It is necessary to demonstrate the replicability of those components of the Project that have resulted in an impact for improving the conditions in which the developmentally disabled can receive maximum benefits from the services they need. Successful replication in other selected sites can demonstrate to the UCPA organization the precise methods that can be utilized if this organization is to become a dynamic change agent throughout the country. A demonstration of replicability can also be considered by other organizations as they attempt to effect change.

# NEW YORK STATE ADVOCACY MODEL

## GOAL

To facilitate and initiate the program services needed by developmentally disabled persons and their families throughout New York State by working with local UCPA affiliates, Home Service Directors, State institutions, government agencies, voluntary agencies, state legislators and consumers.

## OBJECTIVE A:

To prepare legislative proposals and promote legislation to meet the needs of the developmentally disabled in the State of New York.

## RATIONALE:

Legislation in the State of New York for the multiply handicapped is inadequate, especially in the following areas:

1. Coordination of State's education, health, mental health, and social welfare programs so that a comprehensive continuum of services is provided for the developmentally disabled of all ages. There is a need for a single department, commission, or council with authority to implement such coordinated services within the State government.

2. Comprehensive educational programs, especially for children below the age of five and for those with multiple handicaps.

3. Vocational training and social adjustment programs.

4. Public transportation for the physically and mentally disabled.

5. Human rights - especially the rights to housing, recreation, transportation, employment, health services, education, and training.

6. Medical services which are geographically and economically accessible.

## OBJECTIVE B:

To motivate and assist in the initiation of new programs and to seek improvement in and/or expansion of existing programs for the mentally, physically, and emotionally disabled in targeted areas of New York State, as determined by statistics on the existence of programs as documented by the 1972 New York State Developmental Disabilities Council Report, local surveys and data, and the availability of funding sources.

RATIONALE:

The expansion and creation of new programs is necessary in order to fill service gaps for the developmentally disabled as they have determined by local surveys and data, and by the 1972 New York State Developmertal Disabilities Council Report.

OBJECTIVE C:

To promote the active involvement of consumers (disabled adults and parents) in the planning policy-making and monitoring of services on a statewide and local level through their participation in the State Advocacy Council and at least four Local Advocacy Councils.

RATIONALE:

Program services established for the developmentally disabled should be responsive to the needs of consumers themselves as they define these needs. Too often services are developed to fill agency or professional needs without regard for consumers. As was documented in a 1971 survey of UCPA agencies, in recent years neither the disabled nor their parents have been significantly involved in the planning, policy-making and monitoring of services. By establishing and supporting consumer advocacy groups in targeted areas throughout the State, the Advocacy Project hopes to create a model that will be emulated by local affiliates. It also intends to support consumers in their efforts to make an impact on existing service delivery systems.

OBJECTIVE D:

To work with four targeted State institutions in planning strategies by which residents of the institutions may enter community based service programs for the disabled.

RATIONALE:

According to surveys made by the New York State Department of Mental Hygiene, more than one-third of the present residents in State institutions for the mentally retarded are capable of functioning independently or semi-independently in the community. The State institutions are over-crowded and their programming is inadequate to enable disabled persons to realize their potential for fulfilling lives as productive and independent citizens within a community. The goal of the State Department of Mental Hygiene and of many concerned voluntary agencies is to find educational, training, and employment programs in the community to which residents of institutions may be transferred. A corollary goal is the procurement of community based residential facilities (group homes, foster homes, hostels, etc.), so that the disabled person can live in a community at the same time that he goes to school or works in that community. At the present time, the number of community resources for residential facilities and day training programs is very limited, especially for persons with physical as well as mental handicaps. The Child Advocacy Project of UCPA of New York State intends to assist State institution staff in the maximum utilization of available community resources and in the development of additional needed programs

four targeted areas.

OBJECTIVE E:

To provide training and assistance to fourteen New York State Home Service Directors in the following areas: a) effective utilization of existing community resources, b) assisting individual clients and their families to excercise their rights to services as stated by law, and c) promoting the initiation of additional services for the mentally, physically and emotionally disabled.

RATIONALE:

The 14 Home Service Directors serve individual clients and their families in local communities throughout the state. A major part of their work consists of mobilizing and coordinating community resources to meet client needs and of intervening with community facilities in behalf of clients. In fulfilling these activities, Home Service Directors are functioning as local advocates. The Child Advocacy Project is focusing on providing training and information that will enhance the Home Service Directors' skills in obtaining and improving the services available to the developmentally disabled.

## SAN MATEO/SANTA CLARA ADVOCACY MODEL

GOAL I:

To identify, describe and assess the targeted programs provided by public and private agencies for the developmentally disabled.

OBJECTIVE

To determine the population served, purpose, duration, frequency, waiting period (if any), and eligibility requirements of each targeted service, as determined by the Local Advocacy Advisory Council (LAAC), that is provided by public and private agencies for the developmentally disabled in the target area.

RATIONALE:

The project needs readily accessible descriptions of what services are available and how they are used by consumers.

GOAL II

To describe and evaluate differences in and barriers to the utilization of services by families with children who are developmentally disabled.

OBJECTIVE

To develop comparative data regarding differences in and barriers to the service delivery system as it relates to high and low income and ethnic groups in the two-county area.

RATIONALE:

Preliminary investigations have identified several barriers to services for the developmentally disabled related to income and ethnicity: for example, (1) some agencies have maximum income eligibility requirements; (2) some have minimum income eligibility requirements (e.g.) they automatically refer AFDC eligible families to public welfare agencies); (3) some agencies have few Spanish speaking personnel; and (4) the limited public transportation services in the two counties makes it more difficult for families without private transportation during working hours to reach some agencies for service.

GOAL III:

To identify services needed and/or changes sought in the service delivery system from the consumer's perspective.

OBJECTIVE

To develop data which will enable the coordinator and local advocacy advisory council to focus project efforts on service delivery problems of

the consumers in the target area.

RATIONALE:

The project is oriented toward consumer views of service delivery. The consumer with the appropriate resources can provide the most useful information regarding his diverse needs and problems.

GOAL IV:

To strengthen and increase the participation of a diversity of consumer groups and individuals in the planning and delivery of services for developmentally disabled children and their families.

OBJECTIVE

To increase the number of young and/or poor and/or ethnic minority consumers who are members of two principal targeted planning units for the developmentally disabled in the target area:

1. The San Mateo Coordinating Council on Developmentally Disabled

2. The Santa Clara County Advisory Commission on Developmentally Disabled.

RATIONALE

Younger, poorer, and more ethnically diverse consumers have been traditionally excluded from direct representation on planning units of provider agencies.

OBJECTIVE

To develop and implement programs to increase the advocacy functions of groups of consumers in the target area.

RATIONALE

Four predominant methods of advocacy have been used in support of the needs of the developmentally disabled: (1) Community action by voluntary health associations and in some public agencies; (2) Case advocacy by professionals in agencies providing services; (3) Legislative advocacy; and (4) Litigation. Advocacy by groups of consumers is another method which will supplement these four in making the service delivery system more responsive to the diverse consumer population.

# MILWAUKEE ADVOCACY MODEL

GOAL I:

To actively promote and support the participation of the consumer and consumer groups concerned with the developmentally disabled in the determination and development of needed services, and in the monitoring of existing services to the developmentally disabled in order to enable the consumer to become an advocate for his own interests and to establish a framework within which the consumer can participate effectively.

RATIONALE:

The consumer has the greatest degree of involvement with the problems and has the best understanding of the impact of those problems on the developmentally disabled individual and family.

OBJECTIVE A:

To develop consumer awareness of the policies and functions of the project, the advocacy advisory council, and to involve consumers in project activities.

OBJECTIVE B:

To increase consumer effectiveness in advocating for improvement in the service delivery system for the developmentally disabled by increasing consumer participation and influence within the system.

GOAL II:

To provide a channel for cooperative effort on the part of consumers, community representatives and provider agencies.

RATIONALE:

As pointed out in a number of studies, there has been a long history of non-cooperation between provider agencies, resulting in duplication of services, competition between agencies for resources and clientele, fragmentation of services, and lack of agency accountability and responsiveness.

OBJECTIVE A:

To increase, through the Advocacy Advisory Council, cooperation and coordination among service providers, between service providers and consumers, and between service providers and community representatives to reduce competition and minimize fragmentation of services among service providers.

OBJECTIVE B:

To influence, through the Advocacy Advisory Council, the delivery of services to achieve comprehensive and quality services for the developmentally disabled.

GOAL III:

To improve the adequacy and appropriateness of both private and public services to the developmentally disabled.

RATIONALE:

As documented by existing reports and surveys, services to the developmentally disabled are inadequate. Many areas of significant need are not being met by the existing service system.

OBJECTIVE

To develop and conduct an ombudsman program which will advocate for improvement in the availability and delivery of services to the developmentally disabled.

GOAL IV:

To monitor and initiate and influence legislation affecting the developmentally disabled.

RATIONALE:

Legislation is the greatest single influence affecting the provision of service to developmentally disabled persons. The authority, responsibility and funding of services are most often vested in legislative mandate.

OBJECTIVE

To continuously monitor and influence legislative action which affects the developmentally disabled.